



Building Capacity for Health Advocacy at the State and Local Level

Prepared in conjunction with a Grantmakers In Health Strategy Session

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Introduction

The enactment of the Patient Protection and Affordable Care Act (ACA) in March 2010 represents a major achievement—as well as an ongoing challenge—for health advocacy. The historic legislation would not have been possible absent decades of determined work by health advocates at the national, state, and local level. Reform implementation will now require a renewed commitment to health advocacy in order to realize the promise of ACA and ensure that the interests of ordinary citizens are appropriately served.

Health reform portends significant change in nearly all aspects of the health care financing and delivery systems, and state governments will play a pivotal role in determining the nature, magnitude, and direction of these changes. Capacity enhancements in the field of health advocacy—particularly at state and local levels—will be needed to inform the development and implementation of these policies. Additional advocacy capacity is also needed to advance policy priorities, such as health equity and population-based health promotion, which are not fully addressed by ACA.

This paper was prepared in conjunction with a strategy session convened by Grantmakers In Health and sponsored by the Missouri Foundation for Health and The California Endowment. The strategy session was convened to:

- explore the strategic decisions and challenges faced by health philanthropy in developing advocacy capacity at state and local levels,
- share innovative approaches, and
- identify opportunities for collaborative efforts.

This document examines philanthropy's role in advocacy, describes the various sectors that constitute the field of health advocacy, reviews the types of capacities required to effectively engage in advocacy efforts, summarizes different ways health funders have sought to facilitate advocacy capacity development, and highlights key issues for future action discussed during the strategy session.

What Is the Role of Advocacy in Advancing Philanthropic Mission?

Engagement in public policy is viewed as a mission-critical strategy by an increasing number of health funders. This evolving acceptance has been driven by a more nuanced understanding of the legal restrictions that shape foundations' role in the public policy process, as well as a growing recognition that public policy change has the potential to yield wide-scale, sustainable improvements in population health, which cannot be attained through philanthropic action alone.

Funders have broad latitude to inform, influence, and support the implementation of public policy. Figure 1 illustrates the range of policy-relevant activities funders may pursue. A more detailed discussion of the roles philanthropic organizations typically play in the policy arena, as well as an overview of the lobbying restrictions imposed under federal tax law, can be found in the GIH monograph *Strategies for Shaping Public Policy—A Guide for Funders* (GIH 2000).

Figure 1: Public Policy Continuum from Ideas to Implementation

	Problem Definition/ Solution Development	Advancing Solution/ Advocacy	Implementation
Goal	To clearly articulate problem(s) and solution(s)	To build political will to take action	To foster effective implementation
Components of Policy Change	<ul style="list-style-type: none"> • Research and Analysis • Polling • Issue Framing and Messaging • Convening • Engaging Stakeholders • Testing Alternative Approaches 	<ul style="list-style-type: none"> • Advocacy Capacity Development • Coalition Building • Community Organizing • Polling • Message Refinement • Public Education • Education for Opinion Leaders and Policymakers • Media Advocacy • Litigation • Direct Lobbying of Legislators • Grassroots Lobbying 	<ul style="list-style-type: none"> • Public Education • Capacity Development for Government Agencies • Monitoring • Evaluation

Source: Adapted from Holton 2004

Numerous factors dictate where individual philanthropic organizations will choose to focus their energies and resources within this potential continuum of policy engagement. Each foundation must assess its own mission, tax status, scale, scope, political and policy environments, capacities, and willingness to accept risk in order to identify the roles and activities most appropriate to its unique circumstances (The Center on Philanthropy and Public Policy 2003). While a variety of considerations shape philanthropic organizations’ strategic approach to policy engagement, legal parameters represent a threshold issue that dictates the range and scope of strategic options.

Because federal law restricts foundations’ ability to lobby, it is not entirely surprising that some health funders remain cautious about advocacy activities that fall in the middle of this public policy continuum. In light of the common misperception that advocacy is synonymous with lobbying, even health funders that actively support advocacy may be reluctant to use this term to describe their efforts. Others may avoid engaging in any type of advocacy work because they themselves do not understand the distinctions between lobbying and other forms of advocacy. In order to perpetuate a more inclusive and accurate use of the term, GIH utilizes a broad definition of public policy advocacy,¹ which encompasses all types of efforts to influence public policy, including (but not limited to) lobbying activities.

¹ Advocacy is not restricted to the public policy context and may also include efforts to influence the decisions and actions of private sector organizations and individuals. For the purposes of this paper and strategy session, however, the term advocacy is intended to apply primarily to public policy-related efforts.

Definitional Framework

Public policy: decisions and actions of governmental entities (including all branches and levels of government) typically expressed in the form of legislation, regulation, judicial rulings, administrative practices, or funding priorities

Public policy advocacy: organized efforts to influence public policy, including (but not limited to) public education, community organizing, policymaker education, polling, message framing, litigation, and lobbying

Lobbying: a specific type of advocacy activity that focuses on a particular piece of legislation or legislative proposal

- **Direct lobbying:** communicating directly with legislators about specific legislation and providing a view on the legislation
- **Grassroots lobbying:** encouraging citizens to contact their legislators about a specific piece of legislation

Advocacy capacity: the ability to effectively engage in advocacy activities, including sufficient scale of operations and requisite capabilities

Legal concerns are not the only factors that may inhibit philanthropic organizations from supporting advocacy. Some funders may be wary of supporting advocacy efforts because these activities inherently require the adoption of a position or point of view. The objective, science-based activities associated with problem definition and solution development allow funders to remain neutral. In contrast, advocacy entails advancing a particular policy solution (or set of solutions) for a specific problem. Taking a clear stand on an issue may be perceived as risky. Even when broadly defined, policy positions risk alienating those with conflicting views and may make policy-engaged foundations the target of political criticism.

Advocacy may also be perceived as a high-risk undertaking because the policymaking process is complex and somewhat unpredictable. Engaging in health advocacy typically means committing to a long-term, dynamic, and often frustrating process. Funders may not feel confident that their investments will make a difference. They may even be unsure how to measure the impact of their efforts.

More and more funders are finding ways to mitigate these risks and are embracing advocacy as a high-return investment. Some forward-thinking foundations are looking beyond the resources and activities needed to advance specific advocacy objectives and are making capacity development investments designed to more broadly enhance the reach, success, and sustainability of individual advocacy organizations—and the advocacy field as a whole.

Who Engages in Health Advocacy?

Simply stated, the field of health advocacy includes all organized efforts to influence health-related policies. Organizations within the field can typically be categorized by the interests each one seeks to advance, defined in terms of both who is represented and which issues they address. In general, health funders limit their support for advocacy and advocacy capacity development to organizations that represent the constituencies and issues relevant to their philanthropic mission.

The field of health advocacy can be divided into four broad sectors.

- **Dedicated health advocacy organizations whose missions are substantially or exclusively focused on health-related advocacy activities.** The constituencies represented by these organizations span a wide variety of stakeholders, including:

- health care providers, suppliers, insurers, and purchasers (typically represented by trade associations and corporate lobbyists);
- patients affected by a particular disease or disability (such as persons with mental health disorders, children with special health needs);
- populations identified by distinct demographic characteristics (such as infants, children, communities of color, seniors, the uninsured, low-income workers); and
- populations identified by geographic boundaries (such as residents of the nation or a particular state or municipality).

The scope of health-related issues championed by dedicated health advocacy organizations can vary significantly. Some groups may focus on a particular dimension of health policy (such as health insurance coverage, access to care, quality of care, health services research, or nutrition). Others may advocate on a wide variety of health issues depending on the interests of the constituencies they represent and the breadth of their mission. Although the advocacy agenda of some groups may be broad, the relative priority given to specific issues may vary. For example, while some provider groups may advocate for improved access to care, the majority of their advocacy activities may focus on issues that more directly reflect the interests of their members (for example, reimbursement rates, scope of practice). These positions may or may not align with the interests of patients or communities served.

- **Organizations whose missions are substantially focused on advocacy and/or community organizing but for whom health-related issues represent only a limited proportion of their overall advocacy portfolio.** Such groups often represent the broad interests of specific populations (such as children, communities of color, seniors, immigrants, low-income families, unionized workers, faith-based groups, residents of a defined area) or commercial enterprises (such as small business coalitions, industry trade associations). For some of these groups, health may be a significant component of their existing advocacy portfolio. For others, health may represent a very small (or even nonexistent) part of their advocacy efforts, but potential for aligning current interests with health-related goals may exist.

Advocacy & Community Organizing

Although advocacy and community organizing are inter-related activities, groups that focus on community organizing may not identify themselves as advocacy organizations. Community organizers seek to empower individuals to advocate for their own interests and do not attempt to influence or dictate the issues or policy change objectives that will be pursued. Groups identified as advocacy organizations typically advocate on behalf of specific communities or populations and often focus on particular areas of substantive expertise. Some organizations engage in both traditional advocacy and community organizing activities.

- **Service and other charitable organizations whose missions are not substantially focused on advocacy activities but who wish to engage in the public policy process.** Such organizations include health care and social service providers, as well as philanthropic organizations, which seek to advocate on behalf of the populations they serve. These

organizations may also wish to advocate for their own organizational interests, either independently or in conjunction with the dedicated advocacy groups that represent them. It is important to note that these organizational interests and priorities may not fully coincide with the interests of the populations served.

- **Public health, Medicaid, and other government agencies.** Government agencies typically play a policymaking role rather than an advocacy role, but agency staffs do have the potential to act as advocates on policy issues that fall outside their immediate authority. For example, a local public health director may urge the local school board to improve the nutritional content of school lunches. Associations that represent various units of government may also contribute to the field of health advocacy.

Organized efforts by each of these sectors may be evident at the national, state, or local level. Many national advocacy/community organizing organizations (whether focused on health or on broader interests) are affiliated with networks of related groups at the state and, sometimes, local level. The nature of these affiliations (such as exclusivity, strength of linkages, duration) can vary substantially across and within networks. Many individual state- and community-level organizations maintain affiliate relationships with multiple national partners. Examples of national advocacy/community organizing organizations² with ties to state and local affiliates³ include the Center on Budget and Policy Priorities, Center for Community Change, Community Catalyst, Families USA, Family Voices, March of Dimes, National Alliance on Mental Illness, National Network of Public Health Institutes, PICO, and Voices for America's Children.

States vary in the number of national networks active within their borders (Community Catalyst 2011a). In some states (California, Illinois, New York, Washington, Ohio, Minnesota, New Mexico, Oregon, Wisconsin), state-level consumer health advocacy organizations maintain affiliate relationships with over 20 national partners. In other states (Wyoming, Alaska, Hawaii, Idaho, Arizona, Delaware, Oklahoma, and South Dakota), only 8 to 12 nationally affiliated networks are represented.

What Capacities Are Needed for Effective Health Advocacy?

Advocacy capacity development needs are likely to differ across the various sectors and levels of policy engagement described above, but these differences have yet to be fully characterized and documented. There is no single, universally accepted construct for identifying the critical capacities needed for effective advocacy. However, a variety of assessments, tools for conducting such assessments, and capacity development resources have explored the multiple capabilities that contribute to advocacy capacity. Examples include the Alliance for Justice's Advocacy Capacity Assessment Tool, TCC Group's Advocacy Core Capacity Assessment Tool, and the Aspen Institute's Advocacy Progress Planner. Each uses its own framework for categorizing and organizing relevant types of capacity, but common themes and concepts are evident across these various tools and resources.

² Refer to Appendix A for a more comprehensive list of national consumer advocacy organizations involved in health reform implementation.

³ Refer to Appendix B for a list of state-level consumer advocacy organizations involved in health reform implementation.

Using an adaptation of the framework developed by Community Catalyst (2006), advocacy capacity can be conceptualized around six major domains, each representing a constellation of related skills, abilities, and resources:

- **Capacity to compile, analyze, and synthesize policy-relevant information** includes substantive, legal, and policy expertise; skills and resources related to methodological design and data collection; analytic capacity (in the form of both human capital and technological supports such as computer hardware and software); scientific credibility; and the ability to focus findings in ways that are both meaningful to policymakers and reflective of the interests represented.
- **Capacity to communicate persuasively** includes both human resource and technological capacities needed to frame and deliver messages in a manner that advances policy change objectives. Related capacities include: understanding the preferences, priorities, and perspectives of intended audiences; skills in written and verbal communication; expertise in multiple forms of mass media communications; relationships with media outlets; ability to monitor media coverage and identify advocacy opportunities; and adequate information technology systems and internet connectivity to support effective electronic, print, and telephone communications.
- **Capacity to mobilize grassroots support** hinges on the relationship of the advocacy organization(s) with the constituencies represented. Related capacities include: a foundation of trust and credibility; a sophisticated understanding of the constituency's needs, concerns, and priorities; an ability to obtain and utilize input from grassroots constituencies in crafting policy change proposals; and effective and efficient mechanisms for eliciting and facilitating grassroots engagement in advocacy efforts.
- **Capacity to form and maintain alliances and coalitions** focuses on the relationships between and among organizations engaged in advocacy efforts. Related capacities include: the ability to recognize common goals and objectives; the ability to share plans, information, and resources; the ability to coordinate and harmonize efforts; and the ability to productively resolve conflicts.
- **Capacity to identify and act on policy change opportunities and threats**⁴ includes access to and relationships with policymakers, an informed understanding of the complexities of the policymaking process, awareness of opponents' views and activities, and the ability to harness and orchestrate capacities in other domains to influence decisionmaking. Related capacities include: the ability to both anticipate impending opportunities or threats and synchronize responsive advocacy activities in a timely manner, the ability to adapt advocacy tactics to evolving political dynamics, and the ability identify champions and other key decisionmakers.

⁴ Community Catalyst identifies this domain as the "capacity to develop and implement health policy campaigns." Because campaigns are often associated solely with legislative issues, GIH has modified this nomenclature to suggest a broader range of policy change vehicles, including regulatory change, litigation, and administrative practices.

- **Capacity to sustain advocacy efforts** focuses on maintaining the resources (human, financial, and capital) needed for long-term engagement in advocacy activities.

This framework was designed to describe the capacity of an advocacy field as whole, rather than the capacities of specific organizations. This systems perspective stresses that collaboration among organizations is often the most effective and efficient way to develop adequate capacity. Viewed in this way, advocacy capacity is determined by the collective skills, knowledge, motivation, and resources available to individuals participating in aligned advocacy activities.

These major advocacy capacity domains are not mutually exclusive concepts; rather, they reinforce and rely on each other in a variety of ways. Deficits in some domains may be moderated by strengths in other areas. These domains focus exclusively on advocacy capacity and do not fully address more general organizational capacities related to governance, management, fiscal solvency, and accountability that are needed to ensure the long-term viability of the various organizations that participate in health advocacy.

Available evidence does not provide a comprehensive picture of existing health advocacy capacity across the country⁵. However, several available multistate assessments offer insights into the nature of the health advocacy field and related capacity development needs (Community Catalyst 2011a; Community Catalyst 2006, 2010; Mathematica Policy Research 2009). Taken together these studies suggest:

- **Health advocacy capacity varies significantly across states.** In some states (such as California, Colorado, Illinois, Maryland, and Massachusetts), the capacity of health advocacy organizations is relatively strong and networks are fairly well coordinated. In other states, capacity is fairly weak, with relatively few under-resourced organizations engaged in state-level health advocacy and poor coordination among state-level advocates and community-based organizers.
- **Capacity correlates with resource availability.** The availability of resources to support advocacy activities and capacity building efforts is perhaps the strongest predictor of capacity levels. Foundations are the dominant source of funding for the advocacy efforts of organizations that engage in these activities. Some organizations have expanded their funding base to include donor support and other forms of financing, but foundation support remains critical.
- **Even in states with relatively strong capacity, numerous opportunities for improvement exist.** In an evaluation of the Robert Wood Johnson Foundation's Consumer Voices for Coverage (CVC) initiative, Mathematica Policy Research (2009) found that in the 12 states selected through a competitive process, capacities in all six domains identified by Community Catalyst were only moderately well developed.
- **Capacity improvements related to resource development, grassroots support, and communications appear most urgent.** The CVC evaluation found that policy analysis tended to be the most well-developed capacity domain. In contrast, resource sustainability

⁵ Existing multistate assessments of health advocacy capacity focus largely on consumer health advocacy.

was the least well-developed capacity, followed closely by grassroots support and communications expertise. Similar findings were confirmed in a more recent study of all 50 states (Community Catalyst 2011b). Approximately 44 percent of state-level consumer health advocacy organizations report that their capacity to engage in resource development/fundraising is weak, compared to 40 percent identifying weak capacity related to grassroots organizing, and 19 percent reporting weak communications capacity.

- **Capacity development needs are particularly severe in health advocacy organizations that represent communities of color.** Advocacy organizations based in, and focused on, state capitals (typically policy- and legal-oriented organizations) rarely have diverse staffs and may struggle to authentically represent the interests and needs of communities of color. Only 26 percent of state consumer health advocacy organizations identify health equity as a top priority, and just 30 percent of such organizations claim to have strong expertise on this issue (Community Catalyst 2011b). Grassroots and membership-based organizations may be more likely to prioritize health equity and employ diverse staffs, but these organizations also face significant challenges in maintaining vibrant relationships with the communities they represent.
- **The political context in which advocacy organizations and networks operate varies significantly.** Advocacy organizations and networks face different political and partisan obstacles to advancing their policy objectives. Often the policymaking environment is least receptive in states with the most poorly developed health advocacy capacity.
- **Opposition forces tend to be well organized and resourced.** Organizations advocating on behalf of community and consumer interests do not operate in a vacuum. Opposition to policies that promote community health can be strong, and the organizations that advocate on behalf of these interests tend to have well-developed advocacy capacity. The industries and interest groups opposing policies that promote community health invest significant resources in ensuring a robust and effective advocacy voice.

How Have Health Funders Supported Health Advocacy Capacity Development?

Health philanthropies have played a critical role in building health advocacy capacity to represent community interests, particularly the interests of vulnerable populations, and have invested in a variety of different types of capacity development.

Core Operating Support

Funders have recognized that adequate, committed financial resources represent a critical dimension of advocacy capacity for dedicated advocacy organizations, as well as service providers engaged in advocacy efforts. While program grants for specific advocacy campaigns or advocacy-related projects are an important source of financial support, core operating support offers a number of advantages for advocacy capacity development. Core operating support provides a flexible, yet secure, platform for capacity building efforts. Longer-term commitments for core support allow advocacy organizations to attract talented staff with stable employment opportunities. Such funding

allows grantees to adapt the focus of their advocacy efforts to changing community needs or political opportunities in ways that restricted program grants may not. Core operating support also relieves grantees of the labor-intensive development and reporting activities typically needed to secure and manage program grants. The provision of core operating support also allows private foundations to fund organizations that lobby without violating legal restrictions.

Training and Leadership Development

Training and leadership development activities primarily focus on building the skills, knowledge, and competencies of individuals working within the field of health advocacy. Such training and development activities have taken many forms. Some training opportunities and resources have been specifically designed and conducted by foundations for their grantees. Foundations have also supported organizations (such as Community Catalyst, Alliance for Justice, Center for Community Change, and the Herndon Alliance) to develop and make training available to the field. Alternatively, some foundations have sponsored the costs of training identified by grantees and provided by third-party trainers. Others have supported curriculum development or scholarship programs in academic institutions.

The structure and content of advocacy-related training varies widely. Trainings often focus specifically on effective ways to influence the policy process. However, they may also emphasize the development of particular technical skills (such as analytic or communications capabilities), cultural competency, or topical expertise. Trainings may be conducted in-person or through web-based forums. They may be designed as a series of workshops that progressively build on foundational knowledge, or they may be intended as stand-alone activities.

Leadership development represents a special type of training that typically involves a long-term developmental commitment to individuals who are identified through a rigorous selection process. Leadership development activities often rely on both didactic training and experiential learning opportunities. Advocacy may be one aspect of a broader leadership development experience or may be the sole focus of development.

As an outgrowth of its evaluation of advocacy efforts related to the State Children's Health Insurance Program reauthorization, The Atlantic Philanthropies recently sponsored a study of advocacy training, which was conducted by The Headwaters Group. Based on interviews with trainers, experts, and funders, the study sought to both characterize the nature of available training and identify ways of optimizing training opportunities. While advocacy training is rarely evaluated

Advocacy Trainers

Alliance for Children and Families
Alliance for Justice
Aspen Institute
Center for Community Change
Center for Lobbying in the Public Interest
Center for Progressive Leadership
Center on Budget and Policy Priorities
Every Child Matters Education Fund
First Focus
Georgetown University Center for Children and Families
Grantmakers for Effective Organizations
Harvard Family Research Project
Innovation Network
League of Conservation Voters
Midwest Academy
Mosaica
National Community Development Institute
PolicyLink
Social Policy Research Associates
Spitfire Strategies
State Environmental Leadership Program
TCC Group
Voices for America's Children
Wellstone Action

Source: The Headwaters Group 2009

formally, trainings perceived as effective appear to share some common characteristics. Such trainings are typically:

- tailored to the needs and circumstances of participants,
- conducted by trainers with firsthand advocacy experience who are familiar with the political and policy context in which participants must operate,
- inclusive of a broad group of individuals within targeted organizations,
- adequate in duration and intensity,
- designed to include opportunities for participants to practice their advocacy skills, and
- implemented in conjunction with other types of capacity development efforts that broadly build organizational capacity for advocacy.

This final element of effective training was echoed throughout Headwaters' final report, which emphasized that training must be coupled with other types of capacity development supports in order to have a long-term impact.

Technical Assistance

Training opportunities are sometimes coupled with technical assistance resources to reinforce and augment training-related skill building. Technical assistance is typically provided by a third party intermediary when specialized skills and expertise are needed to enhance an organization's advocacy capacity. In some cases, technical assistance activities aim to build the internal capabilities of grantee organizations in addition to providing short-term operational assistance. In other cases, the technical assistance is meant to expand grantee capacity only on a short-term basis.

Communications, policy research, legal counseling, and evaluation are types of technical assistance frequently sought by organizations engaged in advocacy, but assistance related to fundraising, governance, or other operational concerns is not uncommon. Health funders may allow grantees to independently identify the technical assistance resources to be accessed, or they may contract with one or more technical assistance providers to deliver specific services to a cohort of grantees. The latter technical assistance mechanism is often provided in tandem with grant support for specific advocacy activities.

Technical assistance may be provided by not-for-profit capacity building intermediaries or for-profit consultants, but support from other advocacy organizations is also an important source of technical assistance expertise. In addition to partnering on advocacy initiatives, national advocacy organizations often serve as training and technical assistance resources for affiliated advocacy organizations at the state and local level. State and local advocates may participate in multiple national networks, accessing technical assistance from a variety of sources. These advocacy networks foster both operational and capacity building relationships and typically reflect ongoing interaction

among participating organizations. Funders often seek to leverage the long-term relationships represented in these networks to build state and local capacity.

Support for Peer-to-Peer Learning and Network/Coalition Development

Facilitating collaborative relationships among organizations that engage in health advocacy is a particularly important, as well as challenging, undertaking. As described in GIH's recent publication *Implementing Health Care Reform: Funders and Advocates Respond to the Challenge* (2010), a diverse set of advocacy networks and coalitions has been developed to facilitate collaboration among organizations within a region or state, across states, or between state and national organizations. Ideally, such networks and coalitions leverage the strengths and expertise of each participating organization to the benefit of all partners.

Health funders have sought to foster peer-to-peer learning, improve communications, stimulate resource sharing, and support coalition development in a variety of ways. Trainings often serve as an initial, nonthreatening mechanism for bringing together organizations with potentially aligned advocacy goals. Some funders have also convened advocates specifically to coordinate plans and develop collaborative strategies. Others have used grants for advocacy campaigns as incentives for partnership development, encouraging (or even requiring) advocacy groups to come together to develop integrated proposals. In some cases, funders have sponsored “glue” organizations and tools to ensure communication and coordination across the advocacy network. Formal coalitions often receive dedicated funding for staff and resources, allowing the “hub” organization to interact with members, orchestrate activities, and mediate conflicts that may arise. Foundations may also fund individual advocacy organizations to take part in collaborative initiatives.

Advocacy Capacity Assessment

A number of funders have supported advocacy capacity assessments conducted by third parties, as well as the development of tools to guide organizational self-assessment. These capacity assessments allow organizations and/or networks of organizations to systematically examine their current capacities and identify gaps in existing capabilities. Several health funders sponsored the Alliance for Justice's efforts to develop its Advocacy Capacity Assessment Tool. Some funders may encourage or require advocacy grantees to engage in a formal capacity assessment in order to prepare for the receipt of advocacy grants or capacity development resources.

In addition to helping organizations recognize competencies that need to be strengthened, pre-development assessments also offer a baseline that can be incorporated into evaluative studies to determine the impact of capacity building investments. Foundation boards may be reluctant to sponsor capacity development in general (and advocacy capacity development in particular) because of perceived obstacles regarding measurement and accountability. Formal capacity assessments provide a useful metric for monitoring progress toward goals and facilitate oversight of capacity development investments.

What Steps Need to Be Taken to Build Advocacy Capacity in the Future?

The health funders, advocates, and experts convened for the strategy session represented a diverse mix of organizations with different missions, resources, history, and perspectives. Not surprisingly, participants' future priorities for advocacy capacity development varied. Although the focus and emphasis of individual organizations' future health advocacy goals and activities differ, a remarkable level of consensus emerged regarding the demands now facing the field of health advocacy as a whole and the need for accelerated capacity development, particularly at state and local levels.

ACA has amplified the need for health advocacy at the state and local level. Throughout the strategy session discussion, participants noted how federal health care reform has reshaped the health advocacy landscape by initiating a cascade of policy decisionmaking activities, creating new platforms for advocacy engagement, and underscoring the need for collaboration. The scope and pace of implementation activities, combined with political uncertainty and constrained economic conditions, create a host of capacity development challenges for advocates and the health funders that support these efforts. Participants discussed a range of advocacy capacity development challenges related to ACA implementation, as summarized below.

Insurance reforms have created unprecedented and technically complex advocacy needs. Insurance coverage expansions represent the keystone to support ACA's broader delivery system and payment reform architecture and are arguably the most ambitious, groundbreaking provisions within the legislation. These coverage expansions—through the creation of new insurance products and exchanges, regulatory protections for consumers, and major changes in Medicaid eligibility criteria—hinge on policies that will be established by states. Implementation of these reform provisions will require health advocates to interact with potentially unfamiliar policymaking entities (such as state insurance commissions) and to engage in the establishment and conduct of novel decisionmaking processes (such as annual rate reviews by U.S. Department of Health and Human Services to identify unreasonable increases in insurance premiums and the presumed referral of these violations to state regulatory bodies for corrective action).

These types of activities involve highly complex and technical issues in which health advocates may be poorly prepared to engage. For example, nearly two-thirds of existing state-level consumer health advocacy organizations report having inadequate expertise in private insurance market issues (Community Catalyst 2011b). The pressure of “getting up to speed” will be particularly acute in areas of the country that have had limited prior experience with state-level reforms in the individual and small group insurance market.

Improved grassroots advocacy and consumer education is needed to ensure that the public understands the benefits and limitations of reform. Public education and community engagement activities require somewhat different skill sets than the “inside” advocacy used to inform regulatory agencies and policymakers. Such efforts rely heavily on strong communications capacity to identify target audiences, craft compelling messages, and identify effective media outlets and other dissemination mechanisms. Most state-level consumer health advocacy organizations engage in public education (74 percent) and perceive their communications capacity to be at least satisfactory (81 percent) (Community Catalyst 2011b). However, advocates may be underestimating the challenges and capacity needs related to effective public communications.

Strategy session participants were somewhat less confident in the adequacy of existing communications capacity within state health advocacy organizations. Participants noted that health advocates need to build such capacity internally and many could benefit from technical assistance to improve their skills. Unfortunately, potential sources for such technical assistance are somewhat limited. Only about half of all national consumer advocacy organizations report engaging in major activities related to communications and public education in order to support state implementation of health reform. Even fewer engage in the most sophisticated types of communications activities, such as opposition response and message development.

Advocacy strategies and capacity development efforts must be tailored to the specific policy challenges and existing advocacy infrastructure within each state. The political environment and momentum for reform implementation differs across states, with some actively opposing reform, some moving forward cautiously, and others working diligently to meet implementation deadlines. These different environments create different demands and priorities for advocacy organizations. At the same time, existing advocacy capacity also varies across states. Often, consumer health advocacy capacity is least developed in those jurisdictions most opposed to reform implementation. Advocacy capacity development must be based on a nuanced understanding of jurisdiction-specific needs and requirements. State-specific assessments of advocacy capacity needs are available to interested funders from Community Catalyst upon request.

Effective collaboration among state and national advocacy organizations is vital. National advocacy organizations are well positioned to both assist state-level advocacy efforts and facilitate the involvement of state advocates in ongoing federal policy deliberations. Federal regulation establishes important implementation standards for health reform, such as insurer disclosure requirements and the minimum medical loss ratio determined through federal rulemaking. National advocacy organizations will play an important role in monitoring and informing the development of these regulations, but input from state and local consumer groups is also critically needed in order to balance the vocal and powerful opposition of insurance industry representatives. On the legislative front, the new Congress will be considering modifications to ACA. Implementation experiences from states and consumer support will be extremely influential in these debates.

ACA's breadth demands a wide variety of advocacy activities and roles. Although many advocates and funders are deeply involved in the implementation of ACA's insurance-related provisions, some view these issues as too distant from their core competencies to warrant engagement. However, the broad scope of health reform suggests a potential implementation role for all health funders and advocates. ACA touches on virtually all aspects of health care financing and delivery—seeking to stimulate significant change in a variety of domains, including expanded support for safety net providers, research and incentives to promote clinical innovation, and increased recognition of preventive and population-based approaches to health improvement. Advocacy will be needed to ensure that these efforts are carried out in a manner that maximizes their potential, as well as to protect these fledgling programs in looming budget battles. Most of these activities, which seek to transform delivery system practices and population-based interventions, depend on annual appropriations, the debate of which promises to be contentious in Washington and state capitals.

The opportunities presented by health care reform magnify the strategic relevance of addressing advocacy capacity deficiencies. Many of the capacity development needs described above may have existed pre-reform. Yet reform has fundamentally altered the role of health advocates—requiring attention to a broader variety of issues, expanding the range and complexity of relevant policymaking mechanisms, and

crystallizing the importance of public support and engagement. Rising to these challenges will require unprecedented levels of collaboration among funders and advocates to ensure an efficient mobilization of scarce advocacy resources.

Funders and advocates should work to ensure that the urgency of ACA implementation will expedite—rather than eclipse—strategic capacity development goals, such as building advocacy capacity in communities of color. Strategy session participants recognized some degree of tension between the immediate advocacy capacity enhancements needed to implement health reform successfully and the longer-term, strategic capacity development required to advance broader health policy goals. The time-sensitive nature of reform may urge targeted capacity development in moderately strong advocacy organizations that are well positioned to expand or improve their capabilities. However, participants stressed the need to continue investment in historically under-resourced communities and issue areas that may require more extensive structural supports.

Participants emphasized that more energy and new approaches are needed to both achieve health equity and ensure that communities of color have a strong voice in health policy decision-making. Achieving this vision will mean addressing a variety of persistent and compelling needs including the need for 1) additional efforts to promote civic engagement and community organizing in communities of color, 2) more meaningful collaboration between community organizers and health advocates, 3) an increased emphasis on health equity within health advocacy organizations, and 4) more people of color in leadership positions within health advocacy organizations.

Numerous strategies to address these needs have been pursued, including leadership development programs and organizational development activities. While some of these interventions appear promising, others have failed to yield lasting capacity improvements. Strategy session participants encouraged rigorous evaluation and unflinchingly candid self-assessments to both identify effective approaches and determine what lessons can be learned from disappointing investments. Participants discussed critical aspects of successful efforts and noted the importance of relationship building, in addition to skill building, and the crucial need for long-term commitments and realistic expectations. Cautions were raised about isolating advocacy capacity development within communities of color from broader capacity development efforts. Participants emphasized the value of leadership development activities that encouraged networking with advocacy peers, as well as with business leaders and policymakers.

The financial stability and sustainability of advocacy organizations representing communities of color was cited as a significant concern. Participants acknowledged the need for more effective approaches to organizational development and stressed the challenges inherent in establishing new organizations or in expanding the functional capacity of organizations that might already be struggling to deliver core services. The crucial role of not-for-profit governing boards in assuring financial sustainability and supporting advocacy activities was also discussed. Participants agreed that ensuring the sustainable presence of communities of color in health policy debates will require long-term investments and development plans and emphasized the need for best practice models that can be more broadly replicated.

An expanded and diversified funding base for health advocacy is needed. Financial concerns are by no means restricted to organizations advocating on behalf of communities of color. Strategy session participants recognized the need for increased funding to support advocacy efforts and

considered ways to encourage higher levels of investment by philanthropy. Future actions discussed included discrete steps, such as developing future GIH programming related to policy advocacy, as well as more complex undertakings, such as establishing matching or challenge grants and engaging foundations that have not traditionally funded in the health arena.

Participants hope to encourage funders not actively engaged in advocacy activities

to pursue these types of investments. The need for a more diverse funding base for health advocacy activities was viewed as critical, not only for ensuring the financial sustainability of advocacy organizations, but also for maintaining the credibility and independence of advocates. Participants discussed the advantages and challenges of fundraising based on small gifts from multiple donors and stressed the need for more technical assistance regarding these types of financial development activities.

A recent report commissioned by The California Endowment confirms that significant investments in state-level health advocacy are needed to support ACA implementation (Community Catalyst 2011b). The report's authors, representing a coalition of national consumer advocacy organizations, estimate that \$17 million will be needed each year for the next several years to support advocacy capacity related to ACA implementation in all 50 states and the District of Columbia. For individual states, resources required for advocacy related to health reform range from \$178,500 in states with relatively small populations to \$ 928,800 in the most populous states, as summarized in Figure 2. It should be carefully noted that these estimates are based on the level of resources need to support basic consumer health advocacy activities. Additional funds would be required to support a truly robust, comprehensive health advocacy infrastructure capable of addressing a broad range of health-related priorities.

Affordable Care Act Implementation Fund

Community Catalyst has established a new grant fund to support state-based health advocates in ensuring effective and consumer-focused implementation of the Affordable Care Act. Sixteen have been selected for the initial round of funding. Proposals have been requested from California, Maryland, Minnesota, New Jersey, New York, and Washington, and letters of interest have been requested from Colorado, Florida, Illinois, Massachusetts, New Hampshire, North Carolina, Ohio, Oregon, Utah, and Virginia. In order to foster collaboration and coordination among advocacy organizations, Community Catalyst is accepting only one application from each eligible state. The first round of grant awards will be made in March and April 2011.

Figure 2

State System of Advocacy Infrastructure		Level of Effort Based on Population			
		Small	Medium	Large	Largest
		< 4 M	4 - 10 M	10-20 M	>20M
TOTAL PER STATE (plus DC)/YEAR		\$ 178,500	\$ 340,500	\$ 643,500	\$ 928,800
States in Each Category Listed Above	51	Small	Medium	Large	Largest
AR, AK, CT, DC, DE, HI, IA, ID, KS, ME, MS, MT, NE, NH, NM, ND, NV, OK, RI, SD, UT, VT, WV,WY	24	\$ 4,284,000			
AL, AZ, CO, IN, KY, LA, MA, MD, MI, MN, MO, NJ, NC, OR, SC, TN, VA, WA, WI	18		\$ 6,129,000		
FL, GA, IL, MI, OH, PA	6			\$ 3,861,000	
CA, NY, TX	3				\$ 2,786,400
AGGREGATE TOTAL FOR ALL STATES (plus DC)/YEAR				\$17,060,400	

Source: Community Catalyst 2011b

Philanthropic organizations should examine their own advocacy capacity development needs. Foundations are increasingly assuming more active, direct roles in advocacy activities and are leveraging their credibility and community standing to take highly visible positions on key policy issues. Determining if and when a foundation should put its name and reputation directly behind an advocacy issue can be a daunting decision. Funders assuming these direct advocacy roles face many of the capacity development challenges that confront traditional advocacy organizations. Direct advocacy often represents a novel undertaking for health funders that is not supported by existing competencies. Foundations seeking a more direct advocacy role must often build their internal communications capabilities and develop new management and governance processes to ensure that advocacy activities advance organizational mission and complement more conventional grantmaking activities.

Conclusion

Advocacy capacity development is a challenging, yet valuable, undertaking. Advocacy and capacity development each represent a complex, difficult-to-measure goal with a long time horizon. Taken together, advocacy capacity development suggests a heroic enterprise. The magnitude of this challenge has the potential to confound policy change initiatives and may even deter some philanthropic organizations from engaging in advocacy capacity development work.

A number of funders have invested significant resources into building health advocacy capacity, and these investments have yielded important progress, particularly in areas that have benefited from the concerted efforts of multiple funders. These activities, however, are often formulated in response to the compelling needs associated with an immediate advocacy objective, rather than a deliberate, well-planned strategy for long-term capacity development. Similarly, collaboration among philanthropic organizations is frequently ad hoc and opportunistic.

A more coordinated approach may be required to ensure adequate health advocacy capacity capable of engaging at all levels of government. Capacity at the state and local level appears extremely uneven across the nation. Development needs related to resource sustainability, grassroots support, and communications appear particularly urgent. Amplifying the voice of communities of color within the health advocacy field will likely require special emphasis. As funders seek to address these various advocacy capacity development needs, they may need to critically reassess the range, mix, focus, and intensity of the capacity building assistance they provide, as well as explore additional opportunities for collaborative action.

Appendix A: National Consumer Health Advocacy Organizations

American Federation of State, County and Municipal Employees
American Public Health Association
Center for American Progress
Center for Rural Affairs
Center on Budget and Policy Priorities
Children's Defense Fund
Community Catalyst
Faithful Reform in Health Care
Families USA
Family Voices
Georgetown University Center for Children and Families
Georgetown University Health Policy Institute
Health Care for America Now
Health Law and Policy Clinic of Harvard Law School
Herndon Alliance
Main Street Alliance
Medicare Rights Center
National Association of Community Health Centers
National Center for Law and Economic Justice
National Coalition on Health Care
National Health Law Program
National Immigration Law Center
National Partnership for Women and Families
National Women's Law Center
Northwest Federation of Community Organizations
PICO National Network
Progressive States Network
Raising Women's Voices
Sargent Shriver National Center on Poverty Law
Small Business Majority
Trust for America's Health
Universal Health Care Action Network
U.S. Public Interest Research Group
USAction
Voices for America's Children

Source: Community Catalyst 2011b

Appendix B: State-Level Consumer Health Advocacy Organizations

Alabama

- Alabama Appleseed Center for Law and Justice, Inc.
- Arise Citizens' Policy Project

Arizona

- Children's Action Alliance

Arkansas

- Arkansas Advocates for Children and Families
- Arkansas Community Organizations

California

- California Budget Project
- Children Now
- California Pan-Ethnic Health Network
- Health Access California

Colorado

- All Kids Covered
- Colorado Consumer Health Initiative
- Colorado Center on Law and Policy

Connecticut

- Connecticut Citizen Action and Research Groups
- Connecticut Voices for Children

District of Columbia

- District of Columbia Fiscal Policy Institute

Florida

- Covering Kids and Families Florida
- Florida Community Health
- Florida Consumer Action Network Action Information Network
- University of South Florida

Georgia

- Georgia Budget and Policy Institute
- Georgians for a Healthy Future
- Georgia Rural Urban Summit
- Voices for Georgia's Children

Idaho

- Idaho Community Action Network

Illinois

- Campaign for Better Health Care
- Sargent Shriver National Center on Poverty Law
- Citizen Action of Illinois Poverty Law
- Voices for Illinois Children

Indiana

- Citizen Action Coalition Education Fund

Iowa

- Child and Family Policy Center
- Iowa Policy Project
- Iowa Citizen Action Network

Kansas

- Kansas Action for Children
- Kansas Health Consumer Coalition

Kentucky

- Advocacy Action Network
- Kentucky Youth Advocates
- Equal Justice Network
- Mountain Association for Community Economic Development
- Kentucky Voices for Health Community Economic Development

Louisiana

- Louisiana Association of Nonprofit Organizations
- Louisiana Budget Project
- Louisiana Consumer Healthcare Coalition

Maine

- Consumers for Affordable Health Care
- Maine Equal Justice Partners
- Maine Center for Economic Policy
- Maine People's Alliance/Maine People's Resource Center

Maryland

- Maryland Budget and Tax Policy Institute
- Progressive Maryland
- Maryland Citizens' Health Initiative

Massachusetts

- Health Care for All
- Massachusetts Budget and Policy Center

Michigan

- Center for Civil Justice
- Michigan Unitarian Universalist
- Michigan Citizen Action Social Justice Network
- Michigan League for Human Services
- Michigan Universal Health Care Access Network

Minnesota

- Minnesota Council of Nonprofits
- TakeAction Minnesota

Mississippi

- Mississippi Economic Policy Center
- Mississippi Health Advocacy Program

Missouri

- Grass Roots Organizing

- Missouri Jobs with Justice
- Missouri Budget Project
- Missouri Progressive Vote Coalition
- Missouri Health Advocacy Alliance

Montana

- Montana Budget and Policy Institute
- Montana Organizing Project

Nebraska

- Center for Rural Affairs
- Nebraska Appleseed Center for Law in the Public Interest

Nevada

- Progressive Leadership Alliance of Nevada Washoe Legal Services

New Hampshire

- Granite State Organizing Project
- New Hampshire Fiscal Policy Institute
- New Hampshire Citizens Alliance
- New Hampshire Voices for Health for Action

New Jersey

- Association for Children of New Jersey
- New Jersey Policy Analyst
- New Jersey Citizen Action/New Jersey
- New Jersey Policy Perspective Citizen Action Education Fund

New Mexico

- Health Action New Mexico
- Organization for Language Educators
- New Mexico Voices for Children

New York

- Citizen Action of New York
- Community Service Society

North Carolina

- Action North Carolina
- North Carolina Justice Center
- North Carolina Fair Share

North Dakota

- North Dakota Center for the Public Good/NDPeople.org

Ohio

- The Center for Community Solutions
- Progress Ohio
- Ohio Faith and Democracy Collaborative
- Universal Health Care Action/Ohio Organizing Collaborative Network

Oklahoma

- Oklahoma Policy Institute

Oregon

- Alliance for a Just Society
- Oregon Health Action Campaign Community Organizations
- Oregon State Public Interest
- Oregon Center for Public Policy Research Group

Pennsylvania

- Action United
- Pennsylvania Partnerships for Children
- Penn Action
- Philadelphia Unemployment Project
- Pennsylvania Budget and Policy Center

Rhode Island

- Ocean State Action
- Rhode Island KIDS COUNT
- The Poverty Institute

South Carolina

- South Carolina Appleseed Legal Justice Center
- South Carolina Fair Share

South Dakota

- South Dakota Voices for Children

Tennessee

- Tennessee Health Care Campaign
- Tennessee Justice Center

Texas

- Center for Public Policy Priorities
- Texas Organizing Project

Utah

- Utah Health Policy Project
- Voices for Utah Children

Vermont

- Public Assets Institute
- Voices for Vermont's Children
- Vermont Campaign for Health Care Security Education Fund

Virginia

- The Commonwealth Institute for Fiscal Analysis
- Virginia Organizing
- Virginia Interfaith Center for Public Policy

Washington

- Washington Community Action Network
- Washington State Budget and Policy Center

West Virginia

- West Virginia Citizen Action Group
- West Virginians for Affordable Health Care

- West Virginia Center on Budget and Policy Health Care

Wisconsin

- Citizen Action of Wisconsin
- Wisconsin Council on Children and Families

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